

Information leaflet for parents/carers

# Necrotising Enterocolitis (NEC)

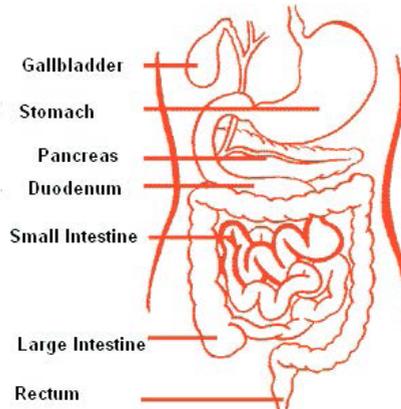


Your baby has been diagnosed with necrotising enterocolitis (NEC). This leaflet will give you more information on the condition and what you can expect.

## Necrotising Enterocolitis (NEC)

NEC is a very serious illness in which the intestine (gut) become inflamed and may die. This can lead to a perforation (hole) developing which allows the contents of the intestine

to leak into the abdomen (tummy). This can cause a very dangerous infection and some babies will die from NEC. NEC can be difficult to diagnose but the symptoms tend to include general signs of illness, problems feeding, and a swollen and tender abdomen. NEC is the most common surgical emergency in newborn babies and tends to affect more babies born prematurely than those born full-term. NEC seems to be becoming more common, but it is likely that this is because more premature babies are surviving



## Treatment and Care After Delivery

In most cases, NEC can be treated without surgery, by resting the intestine by using intravenous feeding (feeding your baby through a drip rather than by mouth) and treating any infection with medication. During this time, your baby will have a naso-gastric (NG) tube passed through his or her nose to drain off the contents of the stomach. Most babies will also need ventilation (help with breathing). They will also have an intravenous infusion (drip) of fluids and medicines.

However, your baby will need an operation if:

- They develop a hole in the gut
- Do not respond to the treatment above
- Their intestine becomes narrowed with scar tissue (strictures).

The operation is carried out under a general anaesthetic (so your baby is deeply asleep) and can last up to 4 hours.

## Feeding

Breast milk is very important for every baby but especially sick babies and even more so for those with bowel/ stomach problems. Breast milk is far more than just food, it contains essential nutrients your baby needs to grow, develop, and recover from surgery or illness.

Although your baby cannot take milk at this time, in order to establish and/or maintain your breast milk supply for when they are well enough to feed, we encourage you to express your breast milk. It is important that you start expressing milk within 6 hours of birth and continue to do this at least 8-10 times a day, including at least once every night.

There is a quiet, private area on the ward that you can use to breast feed your baby or express breast milk. Expressing milk can be done by hand, which is useful in the first few days after birth when you can expect to express small amounts of sticky clear or yellow fluid called 'colostrum'.

Electric breast pumps are available for use on the ward. Your expressed breast milk will be stored safely until your baby is well enough to feed. The nursing staff will be able to show you how to express and store your milk and arrange for you to have access to a breast pump.

## Surgery

The surgeon will explain about the operation in more detail, discuss any worries you may have and ask you to sign a form giving consent for your baby to have the operation. An anaesthetist will also visit you to explain further.

The surgeon may remove any parts of the intestine where tissue has died. The amount removed can vary, but the surgeons will leave as much of the intestine as possible. The surgeons may need to create an artificial way of disposing of waste matter, called a 'stoma'. If your baby has a stoma, the stoma care nurse specialist will visit you and the baby to explain further.

All the surgeons who perform these operations have had lots of experience of caring for newborn babies with NEC.

All operations carry a small risk of bleeding, during or afterwards. Every anaesthetic carries a risk of complications. Your baby's anaesthetist is a very experienced doctor who is trained to deal with any complications.

## After Surgery

Your baby will come back to the intensive care ward to recover, and you will be able to visit as soon as he or she is settled back on the ward. All babies are closely monitored after the operation, and so your baby will be connected to monitors to check his or her breathing, heart rate and oxygen levels. He or she will also be given pain relief through the intravenous infusion (drip).

While your baby's intestines recover and start to work, he or she will continue to be fed through a tube into his or her

veins (total parenteral nutrition or TPN). This will gradually be replaced by breast or bottled milk given through the nasogastric (NG) tube, when your baby is ready for this. As your baby recovers, you may be able to feed him or her from the breast or bottle. Over time, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your baby as much as you feel able while he or she is recovering. This can be daunting, especially while they are connected to drips and monitors, but it will become easier with time. If you are worried about caring for your baby, please talk to the nurses. Your baby will be transferred to another ward within the hospital or to your local hospital, once he or she is feeding properly and gaining weight. Your baby will continue to need to be seen after they have left hospital and you will receive a letter to let you know when the outpatient appointment will be and where.

## **What is the outlook for children with NEC?**

When NEC is successfully treated by resting the intestine, the outlook is good with most children growing up to lead normal lives.

For children who have had surgery, the outlook depends on the amount of intestine removed and how prematurely your baby was born. If your baby had a large amount of intestine removed, he or she may need to stay on TPN for a longer time, sometimes for a year or longer, until the intestine can absorb enough nutrients for normal growth and development.

Further surgery may be needed, for example, closure of the stoma or to help manage intestinal failure.

## Is there a support group?

### **BLISS**

BLISS is a support group which is able to offer support and advice to families with babies with a range of conditions.  
68 South Lambeth Road  
London SW8 1RL

Helpline: [0870 7700 337](tel:08707700337)

Email: [Information@bliss.org.uk](mailto:Information@bliss.org.uk)

Website: [www.bliss.org.uk](http://www.bliss.org.uk)

### **Contact a family**

A UK wide charity offering support, advice and information regardless of a child's condition or disability. Through their Making Contact service they may also be able to put you in touch with other families who are affected by the same disability / medical condition as your child.

Contact a Family  
209-211 City Road  
London EC1 1JN

Freephone Helpline: [0808 808 3555](tel:08088083555)

Email: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

## Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.

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